

A Compendium of HHS Caregiver Support Activities

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Prepared by
Members of the HHS New Freedom Initiative Caregiver Support Workgroup

Introduction

Purpose

The New Freedom Initiative Caregiver Support Workgroup was established to identify and coordinate existing caregiver support activities across agencies within the U.S. Department of Health and Human Services (HHS). The workgroup is a sub-group of the HHS New Freedom Initiative staff group that was established to respond to the President's Executive Order on Community-Based Alternatives. Several solutions outlined in the report to the President, "Delivering on the Promise," seek to enhance HHS support of family caregivers of people with disabilities of all ages. The workgroup will play a leadership role in promoting these solutions as well as coordinating overall HHS caregiver support activities.

The Administration on Aging convened the workgroup and provides leadership and staff support to the workgroup. The first product of the workgroup is this *Compendium of HHS Caregiver Support Activities*. The compendium will be used by the workgroup to catalogue existing efforts to support family caregivers across agencies within HHS and identify opportunities for collaboration and coordination. The compendium is a working document and will be updated on a regular basis as additional caregiver support activities are identified or developed.

Definition

The term caregiver refers to anyone who provides assistance to someone else who experiences limitations in activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs)¹: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS.

Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends, neighbors and volunteers who provide help or arrange for help. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. They provide help with household chores, finances, or with personal or medical needs. This definition does not include formal caregivers who are paid care providers associated with a service system.

¹ ADLs include activities such as bathing, dressing, feeding, toileting, and assistance with walking and transferring. IADLs include activities such as meal-making, managing bills and insurance forms, shopping, housework, and transportation.

Organization of the Compendium

The caregiver support activities outlined in this document are organized by the categories described below. The activities are listed alphabetically by agency name within each category. Specific activities can also be located within the compendium through the index provided on page 65.

Direct Service Programs

The primary focus of the entries included in this section of the Compendium is to directly support family and informal caregivers through the provision of services. These programs may also provide significant support to caregivers while this is not their primary mission.

Planning and Systems Development

The primary focus of the entries included in this section of the Compendium is to provide time-limited financial support for state and local efforts to plan for, and implement, efforts that will create or enhance a system of support for family and informal caregivers.

Research, Demonstrations, and Evaluations

The primary focus of the entries included in this section of the Compendium is to gather new knowledge regarding family and informal caregivers and/or develop new approaches to directly support these caregivers.

Research: surveys of family and informal caregivers to document demographics, need, types and amount of support provided, etc.

Demonstrations: projects to develop and test innovations in service delivery to support family and informal caregivers.

Evaluations: include evaluations of permanent or time-limited direct service programs as well as demonstration projects.

Technical Assistance

The primary focus of the entries in this section of the Compendium is to help states and local communities develop and enhance programs to directly support family and informal caregivers.

Consumer Education, Outreach and Advocacy

The primary focus of the entries in this section of the Compendium is to provide information and education directly to family and informal caregivers to support them in their caregiving role. In addition, some entries in this section support family caregivers in their role as advocates for their loved ones.

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<http://www.aoa.gov>

Administration for Developmental Disabilities (ADD)

<http://www.acf.hhs.gov/programs/add/>

Agency for Healthcare Research and Quality (AHRQ)

www.ahrq.gov

Assistant Secretary for Planning and Evaluation (ASPE)

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Centers for Disease Control and Prevention (CDC)

<http://www.cdc.gov/>

Centers for Medicare and Medicaid Services (CMS)

<http://cms.hhs.gov>

Health Resources and Services Administration (HRSA)

<http://www.hrsa.gov/>

Indian Health Service (IHS)

<http://www.ihs.gov>

National Institute on Aging

<http://www.nia.nih.gov>

Substance Abuse and Mental Health Administration (SAMHSA)

<http://www.samhsa.gov/>

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SECTION I
DIRECT SERVICE PROGRAMS

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Funding Organization: Administration on Aging (AoA)

Purpose: To address the needs of family caregivers nationwide by encouraging all states to increase the availability and efficiency of caregiver support services.

Statutory Cite: Older American Act Amendments of 2000

Start Date: 2001

Eligible Caregivers: Family caregivers of older adults and grandparents and relative caregivers of children not more than 18 years of age (including grandparents who are sole caregivers of grandchildren and those individuals who are affected by mental retardation or who have developmental disabilities).

Types of Support: Components of the systems to be developed in each state include:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and training to caregivers to assist them in making decisions and solving problems related to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

Program Design: This program calls for all states, working in partnership with area agencies on aging and local community service providers to develop comprehensive systems of services to support family caregivers.

Number of Caregivers Served: 250,000

Funding Level: Funded at \$141.5 million in FY 02, approximately \$128 million was allocated to States through a formula based on share of the 70+ population.

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NATIVE AMERICAN CAREGIVER SUPPORT PROGRAM

Funding Organization: Administration on Aging (AoA)

Purpose: To provide multifaceted systems of support services for family caregivers providing care to American Indian, Alaska Native and Native Hawaiian elders and to elders providing care to grandchildren.

Statutory Cite: Older Americans Act Amendments of 2000

Start Date: 2001

Eligible Caregivers: Family caregivers of American Indian, Alaska Native and Native Hawaiian elders and grandparents and relative caregivers of children not more than 18 years old.

Types of Support: Each program is expected to make the following services available: information to caregivers about available services, assistance to caregivers in gaining access to the services, individual counseling, organization of support groups, and caregiver training to assist the caregivers in making decisions and solving problems relating to their caregiving roles, respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities, supplemental services, on a limited basis, to complement the care provided by caregivers.

Program Design: Indian Tribal Organizations and organizations serving Native Hawaiians who receive funding under OAA, Title VI, Part A or Part B are eligible to apply for caregiver support grants.

Number of Caregivers Served: 10,000

Funding Level: Grants totaling \$5.5 million were distributed to 187 Indian Tribal and Native Hawaiian organizations in FY 2002.

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MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER PROGRAM

Funding Organization: Centers for Medicare and Medicaid Services (CMS)

Purpose: HCBS waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing homes or intermediate care facilities for persons with mental retardation.

Statutory Cite: Section 1915(c) of the Social Security Act

Start Date: 1981

Eligible Caregivers: Family caregivers of individuals with disabilities that meet either a hospital, nursing facility or intermediate care facility level of care.

Types of Support: States may choose to offer respite care and caregiver support and education through an HCBS waiver to family caregivers in order to support them in their caregiving role.

Program Design: The Social Security Act specifically lists seven services which may be provided in HCBS waiver programs: case management, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. Other services, requested by the State because they are needed by waiver participants to avoid being placed in a medical facility (such as caregiver support and training, non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care) may also be provided, subject to CMS approval. There are no services that are required to be offered in an HCBS waiver program. Likewise, there is no limit on the number of services that can be offered under a single waiver program.

Funding Level: There are 264 HCBS waiver programs operating throughout the country. All states except Arizona have at least one program. HCBS waiver programs are initially approved for 3 years and may be renewed, with demonstrated successful outcomes, at 5-year intervals.

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INDIAN HEALTH SERVICE CAREGIVER SUPPORT SERVICES

Funding Organization: Indian Health Service (IHS)

Purpose: To provide emotional, physical and financial support to family caregivers caring for tribal elders who are frail and in need of assistance.

Eligible Caregivers: Although dependent on the specific program, generally family caregivers of tribal elders who are frail and determined to need assistance in activities of daily living are eligible to receive services.

Types of Support: Indian Health Service funding (either through IHS directly or tribal programs) provides caregiver support through a number of existing programs. These services are provided in both urban and rural areas. The prevalence of these family caregiver support services in any given community varies and depends both on local health care priorities and on local capacity. Examples of such programs include:

- Community Health Representatives: assistance to family caregivers in hygiene and personal cares; family caregiver education and emotional support; in-home respite for family caregivers; episodic case-management and information/referral for family caregivers; and medical and social transportation for frail elders.
- Public Health Nursing: home visits for medically complicated elders cared for in the home; family caregiver education and emotional support; and episodic case-management and information/referral for family caregivers.
- IHS and tribal hospitals: episodic inpatient respite care (IHS or tribal hospitals); admissions solely for respite; prolonged stays following a necessary medical admission (to allow families to take care of necessary tasks prior to the elder's discharge); and transitional care (after hospitalization outside of home area).
- Medical home visits: in-home assessment and management and family caregiver education and support.
- Emergency Medical Services: medical transportation for medically frail elders and emergent in-home assessment.
- Behavioral Health: emotional support for family caregivers.
- Health Education: educational resources for family caregivers.

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SECTION II

PLANNING AND SYSTEMS DEVELOPMENT

FAMILY SUPPORT PROGRAM

Funding Organization: Administration on Developmental Disabilities (ADD)

Partners: State Councils on Developmental Disabilities; University Centers for Excellence in Developmental Disabilities Education, Research and Services; State agencies; non-profit organizations

Purpose: To strengthen state systems of supports to families of people with developmental disabilities; to ensure that these systems are family-centered and family-directed; to promote family participation and leadership in the development, implementation, and evaluation of family support activities; to promote interagency coordination and collaboration; and to increase funding for family support activities.

Target Population: Families of children with disabilities

Major Activities: Grants are given to states on a competitive basis to develop, implement, expand and/or enhance statewide systems of family support services. The grants are given to state agencies or private non-profit organizations that are designated by governors. Grants are for two years, one year of planning and one year of implementation. The planning grants to States are \$200,000 for planning and \$100,000 for implementation. Grants to territories are \$100,000 for planning and \$50,000 for implementation. All states except California and all territories but Puerto Rico have applied for and received grants under this program.

Funding Level: FY 2001 \$2,300,000. FY 2002 \$3,700,000.

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THE MATERNAL AND CHILD HEALTH SERVICES TITLE V BLOCK GRANT TO STATE PROGRAM

Funding Organization: Health Resources and Services Administration (HRSA)

Partners: State Title V Maternal and Child Health and Children with Special Health Needs Programs

Purpose: The Title V Block Grant Program has as a general purpose the creation of federal-State partnerships to develop service systems to improve the health of all mothers and children in the nation, in keeping with the national Healthy People 2000/2010 objectives.

Statutory Cite: Social Security Act, Title V

Start Date: Oct. 2002

Eligible Caregivers: Families, parents (including fathers) with children and youth with special health care needs (CSHCN), mothers with infants.

Types of Support: At least 16 States and jurisdictions have identified as a state priority with performance measures, developing the capacity to provide family support services for children with special health care needs. For example, Pennsylvania is addressing the need to assure the availability of day care and respite services for children with special health care needs by providing technical assistance, training and incentives to child care givers. New Jersey includes in its Individual Services Plans (ISP) for CSHCN, any enabling services determined necessary, such as respite care and linkages to other services. Hawaii wants to assure that parenting support and information is made available to all families with children. Other states like Kentucky support parenting through home visiting programs or, like the Virgin Islands, promoting better linkages between families and community supports.

Program Design: Each State addresses four core public health services: direct health care services, enabling services, population based services and infrastructure building services. Each State determines its maternal and child health (MCH) priorities, and allocates resources for activities that specifically address those priorities. Most programs include in their enabling services, family support services such as improved access to care giving support and respite care, especially for children with special health care needs (CSHCN).

In addition, all States and jurisdictions are required to build community based systems of care for CSHCN, where health services are coordinated with one another, and health and other services are coordinated across a variety of State and local programs. This requirement would include efforts to coordinate and provide family support services.

Funding Level: FY 2001: \$582.2 million for Formula State Block Grants: 85% of the total budget is allocated to 59 States and other political jurisdictions. The program requires a State match; a minimum of 30% of federal Block Grant funds to be used to support services for

CSHCN, a minimum of 30% of federal funds to be used to provide preventive and primary care services for children; and that States spend no more than 10% of federal Title V funds to be spent on administrative costs.

Evaluation: States submit Title V Applications for Block grant funds and annual reports on progress for review by federal staff and non-federal experts, including families of CSHCN. In accordance with GPRA, Public law 103-62, states must document accountability and report on 18 national performance measures and up to 10 additional state performance measures.

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CIRCLES OF CARE: NATIVE AMERICAN CHILDREN'S SERVICES

Funding Organization: Substance Abuse and Mental Health Services Administration (SAMHSA)

Partners: In FY 1999, a multi-agency collaboration among SAMHSA's Center for Mental Health Services, the Indian Health Service, the National Institute of Mental Health, and the Department of Justice's Office of Juvenile Justice created the Circles of Care program.

Purpose: To support the development of systems of care models designed by American Indian and Alaska Native community members to achieve their selected emotional, behavioral, educational, vocational, and spiritual outcomes for their children.

To improve access to funding to implement the models, evaluate the models' effectiveness, and to develop a body of knowledge about culturally respectful treatment methods for children with serious emotional disturbances.

Target Population: American Indian and Alaska Native youth.

Program Design: The program provides planning grants to tribal and urban Indian programs to plan and evaluate culturally appropriate systems of mental health care for American Indian/Alaska Native children, adolescents, and their families. Technical assistance continues to be provided to grantee organizations by the National Indian Child Welfare Association.

Significant Products: Planning grant awardees are more successful in their application for a six-year award under the Comprehensive Community Mental Health Services for Children and their Families Program.

Funding Level: The program initiative – with 9 grantees in FY 1999 and an additional 7 announced in late FY 2001– was designed by a team of tribal leaders and providers. Federally-recognized tribal entities are the eligible applicants.

Evaluation: The National Center on American Indian and Alaska Native Research is providing technical assistance for a cross-site evaluation.

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COMPREHENSIVE COMMUNITY MENTAL HEALTH SERVICES FOR CHILDREN AND THEIR FAMILIES PROGRAM (CMHS)

Funding Organization: Substance Abuse and Mental Health Services Administration (SAMHSA)

Purpose: To develop and support individualized, community-based systems of care to reduce impairment, improve short- and long-term mental health, and enhance both educational and social functioning of youth with serious emotional disturbances.

Start Date: 1993

Eligible Caregivers: Youth with serious emotional disturbances and their caregivers.

Types of Support: Today, 45 communities are implementing and evaluating the effect of community-specific systems of care on the lives of local children and adolescents with serious emotional disturbances and their families. Individualized case planning, coordination, and other program elements enable communities to integrate child and family-serving agencies (e.g., health, mental health, substance abuse treatment, child welfare, education, health, and juvenile justice) into a community-based system of care.

Program Design: This systems change grant program, which requires communities to match Federal dollars over a six-year award, expands community service capacity for a culturally competent, community-based, coordinated cross-agency approach to serving children and adolescents with serious emotional disturbances and their families. Families must be involved in the planning and development of these grant projects. Families have the primary voice in determining services that are needed to support them in their caregiving role.

Funding Level: Since 1993, 67 six-year competitive awards have been made to 42 States. The awards can total a maximum of \$2 million each. Government entities, tribal entities and territories are eligible applicants.

Evaluation: A mandated evaluation is conducted on an on-going basis.

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SECTION III

**RESEARCH, DEMONSTRATIONS AND
EVALUATIONS**

ALZHEIMER'S DISEASE DEMONSTRATION PROGRAM

Funding Organization: Administration on Aging (AoA)

Partner: Alzheimer's Association

Purpose: To demonstrate how existing public and private resources may improve education, coordination and increase access to home and community-based services for people with Alzheimer's disease and their families.

Target Population: Individuals with Alzheimer's disease and their families, with a particular focus on serving ethnic minorities, low income, rural Alzheimer's families and persons with developmental disabilities and Alzheimer's disease.

Outcomes Specific to Caregivers:

- Receive culturally appropriate support to help them maintain their caregiving role;
- Decrease stress related to their caregiving role by receiving respite; and
- Enhance their ability to provide care to their loved one through the use of program resources and support groups.

Program Design:

Currently, 33 states are receiving funding to develop new models of care and to make changes to their statewide systems of care so they can better respond to the needs of people with Alzheimer's and their families. Examples of projects include:

California Department on Aging, Sacramento, CA, \$350,000 – to develop a system of dementia care for Asian and Pacific Islanders in the Los Angeles and San Francisco Bay area. The system will develop and provide culturally and linguistically competent educational, social, and supportive services for dementia-affected persons and their families.

Maine Department of Human Services, Bureau of Elder and Adult Services, Augusta, ME, \$255,000 – to integrate dementia-specific services for persons with Alzheimer's disease and their caregivers into its long-term care system. Models will be developed to serve people with dementia who are enrolled in a rural Medicaid-coordinated/managed care demonstration program while incorporating mental health services for people with dementia.

Minnesota Board on Aging, St. Paul, MN, \$270,061 – to develop at least five model community-based service projects, train home and community-based direct care workers in culturally appropriate approaches to dementia care, and to develop a community advocates resource "point of contact" in every county. Expand day care and other home and community based services in Native American communities.

New York State Office for the Aging, Albany, N.Y. -- \$305,000 -- To develop direct services to persons with developmental disabilities (DD) and Alzheimer's disease (AD) designed to help them remain in family and group homes in their communities. The project will provide information, training and support group services to family caregivers, and develop comprehensive professional training programs to create an AD/DD competent workforce.

Tennessee Commission on Aging - \$350,000 - The Alzheimer's Respite Services Demonstration project will provide assistance to minority and low income groups and their caregivers. The project will also explore Internet use in assisting families of persons with Alzheimer's Disease and caregivers. The experience of this demonstration will be adapted and replicated throughout Tennessee, thereby improving the responsiveness of the existing home and community based systems of care.

Texas Department of Human Services, Austin, TX, \$265,532 – will develop a culturally and linguistically appropriate assessment process and system of care for Hispanic families who live in the San Antonio and Rio Grande Valley areas. Direct care service gaps will be addressed through development of culturally competent respite and adult day care.

Significant Products: The demonstration projects funded under this program have produced a wide variety of products for use by other service providers, policy makers, families, and individuals with Alzheimer's disease, including:

- Consumer and family education guides/tip sheets, videos, brochures and training;
- Coalition building guidebooks;
- Caregiver support resources and educational modules;
- Program development issue briefs;
- Evaluation of service delivery models and targeting efforts; and
- Culturally appropriate information, training and outreach materials for Latino/Hispanic, African American, some Native American tribes, Asian/Pacific Islander, Hmong, Native Hawaiian, Russian, rural and other hard to reach populations.

Funding Level: \$10.1 million funds demonstration projects in 33 states.

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NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM DEMONSTRATIONS

Funding Organization: Administration on Aging (AoA)

Purpose: To develop innovative approaches to assist families and informal caregivers.

Target Population: Caregivers of older persons and grandparents and older relatives who are caregivers of children.

Program Design: In 2002, 36 projects were funded to develop innovative approaches to assist families and informal caregivers of older persons as well as grandparents and older relatives who are caregivers of children. Examples of these projects include:

- **Pima Council On Aging, Tucson, AZ** - will develop, test and implement a culturally proficient model of family caregiver support to meet the needs of Mexican-American caregivers and elders.
- **Alliance for Aging, Miami, FL** - will demonstrate a 24-hour crisis respite and referral system for caregivers of elders and adults with disabilities. This will increase flexibility and convenience of current services; provide crisis respite for elder caregivers of children and adults with disabilities; recommend ways to reduce stress, and minimize or prevent future crisis events.
- **Easter Seals, Chicago, IL** - will produce a transportation-solutions package that the aging network can use to address caregivers concerns about transporting relatives with behavioral problems; use of assistive technology; best practices of volunteer supported transportation; use of escorts; and the Americans With Disabilities Act.
- **Normandale Ministry for Healing and Wholeness, Edina, MN** - will develop model volunteer care teams who will provide training, respite and resource counseling and tools to help caregivers arrange for other community services as needed.

Funding Level and Status: FY 02, approximately \$6 million was awarded to 36 projects.

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PROJECTS OF NATIONAL SIGNIFICANCE

Funding Organization: Administration on Developmental Disabilities (ADD)

Partners: State Councils on Developmental Disabilities (SCDD), Protection and Advocacy Agencies, Centers for Excellence in Developmental Disabilities Education, Research, and Services, State agencies, State and local non-profit organizations, National Associations

Purpose: To provide grants, contracts, and cooperative agreements to promote promising practices, demonstrate innovative approaches, and address various issues impacting the independence, productivity, integration, and inclusion of people with disabilities in all facets of community life.

Target Population: Persons with developmental disabilities and their families.

Program Design: These Projects focus on the most pressing issues affecting people with developmental disabilities and their families. Project issues transcend the borders of States and territories, while project designs are oriented to permit local implementation of practical solutions. Examples include:

- data collection and analysis;
- technical assistance to program components;
- technical assistance to develop information and referral systems;
- projects which improve supportive living and quality of life opportunities;
- projects to educate policymakers; and
- efforts to pursue federal interagency initiatives.

Funding Level: FY 2001 \$10,915,000. FY 2002 \$11,684,000.

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UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES RESEARCH AND SERVICE

Funding Organization: Administration on Developmental Disabilities (ADD)

Partners: State Councils on Developmental Disabilities, Protection and Advocacy Agencies, University Communities, State agencies

Purpose: The mission of University Centers is to serve as liaisons between academic expertise and institutions of higher learning and service delivery systems so as to positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities.

Target Population: People with disabilities and their family members, service organizations, students, professionals, paraprofessionals, direct-care providers, community leaders and policy-makers.

Program Design: University Centers carry out interdisciplinary training, promote exemplary community service programs, provide technical assistance, and conduct research and dissemination activities, UCEDDs also provide services in many areas including family support, individual support, personal assistance services, clinical services, prevention services, health, education, vocational and other direct services.

Funding Level: FY 2001 \$24 million. FY 2002 \$24 million.

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CENTERS FOR EDUCATION AND RESEARCH ON THERAPEUTICS

Funding Organization: Agency for Healthcare Research and Quality (AHRQ)

Partners: Food and Drug Administration (FDA), Duke University, HMO Research Network, University of Alabama-Birmingham, University of Arizona, University of North Carolina, University of Pennsylvania, Vanderbilt University

Target Population: Centers for Education and Research on Therapeutics (CERTs) partners, including government agencies, academic groups, practitioners, drug and device companies, commercial research groups, or consumer representatives are committed to developing knowledge, managing risk, improving practices, and informing policies to advance the optimal use of drugs, medical devices, and biological products for all members of society. A core value of the CERTs program is the belief that collaboration among groups with different perspectives and resources is critical if the results are applicable in "real world" settings. The centers work with public and private collaborators on projects, that allows each center to expand the number of its projects and extend their potential impact.

Significant Products: CERTs publications and presentations can be found at the CERTs website at <http://www.certs.hhs.gov/resources/index.html>. Recent publications in peer-reviewed journals articles include:

- Shatin D, Drinkard C. Ambulatory use of psychotropics by employer-insured children and adolescents in a national managed care organization. *Ambulatory Pediatrics*, 2002 Mar-Apr; 2(2): 111-9
- Putnam KG, Buist DSM, Fishman P, Andrade SE, Boles M, Chase GA, Goodman MJ, Gurwitz JH, Platt R, Raebel MA, Chan KA. Chronic disease score as a predictor of subsequent hospitalization: a multiple HMO study. *Epidemiology*, 2002 May; 13(3): 340-346
- Ray WA, Stein CM, Byrd V, Shorr R, Pichert JW, Gideon P, Arnold K, Brandt KD, Pincus T, Griffin MR. Educational program for physicians to reduce use of non-steroidal anti-inflammatory drugs among community-dwelling elderly persons: a randomized controlled trial. *Medical Care* 2001; 39: 425-35.
- Sleath B, Rubin RH, Campbell W, Gwyther L, Clark T. Physician-patient communication about over-the-counter medications. *Social Sciences and Medicine*, 2001; 53: 357-69.

Major Activities: Centers for Education and Research on Therapeutics (CERTs) were originally authorized in the Food and Drug Modernization Act of 1997 and began in 1999. The program currently consists of seven centers that emphasize specific therapeutic topics and partnerships with numerous public and private organizations. The CERTs Program is administered as a cooperative agreement by the lead agency, AHRQ, in consultation with the U.S. Food and Drug Administration (FDA). Research conducted by the CERTs program has three major aims:

1. To increase awareness of both the uses and risks of new drugs and drug combinations, biological products, and devices as well as of mechanisms to improve their safe and effective use.
2. To provide clinical information to patients and consumers; health care providers; pharmacists, pharmacy benefit managers, and purchasers; health maintenance organizations (HMOs) and health care delivery systems; insurers; and government agencies.
3. To improve quality while reducing the cost of care by increasing the appropriate use of drugs, biological products, and devices and by preventing their adverse effects and consequences of these effects (such as unnecessary hospitalizations).

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MEDICAL EXPENDITURE PANEL SURVEY

Funding Organization: Agency for Healthcare Research and Quality (AHRQ)

Partner: National Center for Health Statistics

Target Population: The Medical Expenditure Panel Survey is a national probability survey conducted on an on-going basis by AHRQ's CCFS to provide nationally representative estimates of health care use, expenditures, sources of payment, and insurance coverage and quality of care for the U.S. civilian non-institutionalized population. The MEPS sample is drawn from a nationally representative sub sample of households participating in the National Health Interview Survey (NHIS), an annual survey of 42,000 households conducted by the National Center for Health Statistics (NCHS).

Significant Products: Information about survey public use data files and survey related publications, including findings reports, methodology reports, journal article publications, and statistical briefs can be found at the MEPS web page: <http://www.meps.ahrq.gov>.

Major Activities: MEPS collects data on the specific health services that Americans use, how frequently they use them, the cost of these services, and how they are paid for, as well as data on the cost, scope, and breadth of private health insurance held by and available to the civilian, non-institutionalized U.S. population. The MEPS Household Component (HC) obtains data on health care use, expenditures, sources of payment, insurance status, functional limitations and disabilities, restricted activity days, access to care, perceived health status, health conditions, and indicators of quality and satisfaction with care. The survey permits both person-based and family-level estimates. The Insurance Component (IC) provides information on premiums; deductible and co-payment provisions; distribution of premium costs across payers; and health insurance options that are linked to the household sample. MEPS periodically over samples populations of interest, such as persons with disabilities, and develops supplements on topics of interest, such as caregivers or long-term care.

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CASH AND COUNSELING DEMONSTRATION

Funding Organization: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Partner: ASPE is partnering with the Robert Wood Johnson Foundation (RWJF) to evaluate the Cash and Counseling Demonstration.

Purpose: To test the feasibility and assess the advantages and disadvantages of a consumer-directed approach to the financing and delivery of personal assistance services (PAS) for people with disabilities of all ages.

To increase consumers' control over their personal care, thereby increasing satisfaction with care and reducing unmet need, without increasing public costs.

Program Design: Begun in 1995, the demonstration is taking place in Arkansas, Florida, and New Jersey. It is a Medicaid demonstration in which beneficiaries with disabilities receive a monthly cash allowance to purchase personal assistance services and related goods, and counseling to help plan these purchases. They may purchase personal assistance from sources other than Medicaid providers, such as family members or friends.

Four broad questions will be addressed in the evaluation:

- How does it affect consumers and their caregivers?
- How does it affect public cost?
- Who participates in the project?
- How was the project implemented?

Preliminary findings from the demonstration are available at www.inform.umd.edu/aging.

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<http://www.inform.umd.edu/AGING/CCDemo/>

INFORMAL CAREGIVING: COMPASSION IN ACTION

Funding Organization: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Partner: Administration on Aging (AoA)

Purpose: To raise awareness about informal caregiving so that the leaders of all segments of society – including policymakers, educators, the clergy and the media – acknowledge and celebrate informal caregiving as one of the notable strengths of our Nation’s families and communities.

Target Population: Policymakers, educators, clergy, media, and the general public.

Program Design: “Informal Caregiving: Compassion in Action” is a synthesis of available research on the prevalence of family caregiving, the needs of family caregivers, and the implications of an aging population on the demands of family caregivers.

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STUDY OF LONG-TERM CARE INSURANCE

Funding Organization: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Purpose: To look more closely at how the interaction of long-term care insurance-financed paid care interacts with informal care and how this interaction may influence decision-making on long-term care service use.

Target Population: Policymakers, researchers, state and federal staff working in long-term care.

Program Design: ASPE conducted a study that looked at, among other things, the impact of private long-term care insurance on informal caregiving. As a follow-up to this study, an “admission cohort” study is being conducted to identify how long-term care insurance claimants decide to use their policies to meet their long-term care needs (will they pay for home care, assisted living, nursing facility, etc.). Claimants’ activity will be followed for 18 months to see if they change their patterns of service use and why.

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BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partner: State Health Departments

Purpose: To track health risk behaviors, health conditions and use of health services.

Target Population: Policymakers, professionals who work with older adults, elderly population

Program Design: Through the state-based Behavioral Risk Factor Surveillance System (BRFSS), CDC assists states to learn more about the prevalence of behaviors that place Americans at increased health risk. The BRFSS has focused primarily on four behaviors: physical inactivity, unhealthy diet, tobacco use, and not receiving proven preventive services such as cancer screenings. These personal, health-related behaviors have a tremendous impact on the rates of heart disease, stroke, cancer, and diabetes, which are the nation's leading killers. The BRFSS describes these personal health behaviors in terms of how common they are, whether they are increasing over time, and which populations might be most at risk. The information gathered through this state-based telephone survey system is essential to national, state and local public health agencies as they monitor the impact and effectiveness of selected public health interventions.

At least one State Unit on Aging (North Carolina) has added caregiver-related questions to the BRFSS in order to track caregiver-specific risk factors.

Significant Products: State profiles of BRFSS data are available on the CDC website at: www.cdc.gov/brfss.

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DATA WAREHOUSE ON TRENDS IN HEALTH AND AGING

Funding Organizations: Centers for Disease Control and Prevention (CDC) National Center for Health Statistics

Partner: National Institute on Aging (NIA)

Purpose: To track trends in health status, healthcare use, and health care costs of older population.

Target Population: Policymakers, professionals who work with older adults, elderly population.

Program Design: With the support of the National Institute on Aging, the CDC's National Center for Health Statistics (NCHS) has created a new web-based, user-friendly tool to provide access to up-to-date information on the health of older Americans – the Data Warehouse on Trends in Health and Aging. This system is designed to show trends in health-related behaviors, health status, health care utilization, and health care costs of the older population. A data dissemination tool called “Beyond 20/20®” is used to retrieve and display customized tables of health information on older men and women of various ages, races, and ethnicities. “Beyond 20/20®” can also be used to analyze the data with graphs and maps.

Significant Products: A series of special reports and features have been created from the Data Warehouse and are available from CDC's NCHS website

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NATIONAL PROGRAMS TO SUPPORT HEALTHY AGING

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partner: National Council on the Aging (NCOA)

Purpose: To examine and evaluate over 600 innovative health and supportive programs for older adults.

Target Population: Caregivers of older adults.

Program Design: In this project, CDC is supporting the National Council on the Aging (NCOA) to examine and evaluate promising and innovative programs (from over 625 identified) related to social support and caregiving, chronic disease management, and physical activity among older adults. NCOA will establish a National Program Advisory Committee to guide the development and implementation of this project.

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NATIONAL INSTITUTE ON AGING CAREGIVER SUPPORT RESEARCH

Funding Organization: National Institute on Aging (NIA)

Purpose: To identify effective evidence-based interventions to support individuals providing unpaid care to a family member with a disability.

Target Population: Family caregivers of individuals with disabilities.

Outcomes Specific to Caregivers: Increased caregiver knowledge, skills and well-being; decreased stress of family caregivers associated with their caregiving role; increased perceptions of support and that they “are not alone” by family caregivers; improved emotional, physical and mental health status of family caregivers and care recipients.

Program Design: The NIA funds multiple research projects aimed at improving the support provided to family caregivers. Examples of this research include:

- **REACH: Resources for Enhancing Alzheimer’s Caregiver Health.** Built upon the findings of REACH I, REACH II was funded in 2001 to design and test a single multi-component intervention among family caregivers of persons with Alzheimer’s Disease or related disorders.
- **African-American and White Caregivers: Health Effects.** A sociocultural modification of the stress and coping model of caregiver health and mental health outcomes is used to test hypotheses about the effects of ethnicity and culture.
- **The Family Care Study.** A randomized controlled efficacy trial is being conducted of PREP (Preparedness, Enrichment, and Predictability Program) and a home health intervention to determine the comparable effects on family care variables.
- **Small Business Innovation Research (SBIR).** These grants are for small companies to conduct innovative research or research and development that has potential for commercialization and public benefit. Several are related to products that improve the well-being of caregivers. More information is available at <http://grants1.nih.gov/grants/funding/sbir.htm>

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SECTION IV
TECHNICAL ASSISTANCE

AOA CAREGIVER SUPPORT WEBSITE

Funding Organization: Administration on Aging (AoA)

Purpose: To provide information on the prevalence of family caregiving, the characteristics and needs of family caregivers, and future trends in family caregiving.

Target Population: Policymakers, service professionals, and advocates.

Types of Technical Assistance: The AoA Caregiver Support Website provides the following information:

- Program guidance related to the National Family Caregiver Support Program;
- Commissioned papers from leading researchers on issues related to family caregiving, including systems development;
- Statistics on family caregiving; and
- Links to useful websites and other resources related to family caregiving.

The AoA Caregiver Support Website is available at <http://www.aoa.gov/carenetwork>.

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ALZHEIMER'S DEMONSTRATION PROGRAM WEBSITE

Funding Organization: Administration on Aging (AoA)

Partners: While some of the materials presented in this site were developed through the Alzheimer's Demonstration Program, other information may be from reputable organizations and programs outside AoA.

Purpose: Through this site, families, caregivers, and professionals can find information about Alzheimer's disease, caregiving, working with and providing services to persons with Alzheimer's and where you can turn for support and assistance. Guidance and information is also provided to Alzheimer's Demonstration Program grantees through the website.

Target Population: All individuals and families seeking information about Alzheimer's Disease; Alzheimer's Demonstration Program grantees; and service professionals and policymakers.

Types of Technical Assistance: The Alzheimer's Demonstration Program Website provides the following information:

- Resources for persons with Alzheimer's disease, their caregivers, and families;
- Information on outreach & service delivery model replication for states and community organizations;
- Resources for service professionals developed by Alzheimer's Demonstration Program grantees;
- Program evaluation results and successful service delivery strategies;
- Links to latest research and other useful websites and Alzheimer's resources; and
- Program guidance for Alzheimer's Demonstration Program grantees.

The Alzheimer's Demonstration Program Website is available at <http://www.aoa.gov/alz/>.

Funding Level: FY01: 8,962,000. FY02: \$11,496,000

Number of Caregivers Served: FY01: 5,000 unduplicated individuals with Alzheimer's disease received in-home service; 75,000+ individuals with Alzheimer's disease and their families received personalized information and assistance.

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NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM: TECHNICAL ASSISTANCE TO THE AGING NETWORK

Funding Organization: Administration on Aging (AoA)

Purpose: To assist State Units on Aging, Area Agencies on Aging, and community-based service providers to implement the National Family Caregiver Support Program.

Target Population: Aging Network professionals and service providers.

Types of Technical Assistance: A handbook of resources for professionals was developed as a result of the 1st Annual National Family Caregiver Support Program Conference, held in September 2001. The handbook includes commissioned papers by experts in the field that discuss significant implementation issues that the Aging Network will need to address in the implementation of this program.

The handbook is available on the AoA website at: <http://www.aoa.gov/carenetwork>.

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USER LIAISON PROGRAM

Funding Organization: Agency for Healthcare Research and Quality (AHRQ)

Partners: State and federal government agencies, associations representing state officials, researchers, foundations

Target Population: Local, State and Federal health policymakers

Types of Technical Assistance: The User Liaison Program (ULP), established in 1978, contributes to AHRQ's mission by synthesizing and distributing research results to local, State, and Federal health policymakers-- "users" of such research. Small policy-thematic workshops form the core of ULP's activities, although skill-building workshops, audio teleconferences, and products such as research syntheses and web-based learning tools may also be produced. In addition to providing information and tools with which informed health policy decisions can be made, ULP serves as a bridge between State and local health policymakers and the health services research community, by bringing back to the Agency the research questions being asked by key policymakers.

Significant Products: Workshop summaries, briefing papers, web-assisted audio conferences, and online training products can be found at <http://ahrq.gov/news/ulpix.htm> and include topics such as:

- Managed Care and Persons with Disabilities and Chronic Illnesses,
- Olmstead: Community-Based Services for all People with Disabilities,
- Building a High-Quality Long-Term Care Paraprofessional Workforce,
- Children with Special Health Care Needs: Developing Integrated Systems for Care
- Expanding Long-Term Care Choices for the Elderly,
- Designing Healthcare Systems that Work for People with Chronic Illnesses and Disabilities,
- Strengthening the Rural Health Infrastructure: Network Development and Managed Care Strategies

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ASPE CAREGIVING RESEARCH WEBSITE

Funding Organization: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Purpose: To provide a collection of research regarding family caregiving, including trends, prevalence, and effective interventions.

Target Population: Policymakers, researchers, and service professionals.

Types of Technical Assistance: The ASPE caregiving research website provides information regarding the trends and prevalence in family caregiving, evaluations of interventions to support family caregivers, and links to research and advocacy organizations concerned about family caregiving.

The ASPE caregiving research website is available at <http://aspe.hhs.gov/daltcp/index-c.htm#caregiver>.

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THE AGING STATES PROJECT

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partners: Association of State and Territorial Chronic Disease Program Directors and the National Association of State Units on Aging, with support provided by the Centers for Disease Control and Prevention and the Administration on Aging.

Purpose: To bring together the respective strengths and expertise of the public health and aging services networks to better meet their shared responsibility for ensuring optimal health for our nation's rapidly aging society.

To systematically compile information on health-related needs, activities and partnerships related to older adults in State Units on Aging and State Health Departments. The information will provide an overview of health promotion and disease prevention efforts for older adults and will help identify opportunities for collaboration between the public health and aging services networks.

Target Population: Policymakers, researchers and staff working in aging and health at the state and federal levels.

Types of Technical Assistance: In June 2001, an assessment was conducted of State Health Departments and State Units on Aging on the following information:

- Health promotion needs, priorities, barriers;
- Program support needs;
- Funding sources for health promotion and disease prevention; and
- Organizational and collaboration issues.

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GERIATRIC EDUCATION CENTERS

Funding Organization: Health Resources and Services Administration (HRSA)

Purpose: Improve the training of health professionals in geriatrics, develop and disseminate curricula relating to the treatment of the health problems of elderly individuals, support training and retraining of faculty to provide instruction in geriatrics, support continuing education of health professionals who provide geriatric care, and provide students with clinical training in geriatrics in nursing homes, chronic and acute disease hospitals, ambulatory care centers, and senior centers.

Statutory Cite: Section 753(a) of the Public Health Service Act

Target Population: Health professionals training programs and schools.

Types of Technical Assistance: The grant program is designed to strengthen multidisciplinary training of health professionals in the diagnosis, treatment, and prevention of disease and other health concerns of the elderly. Functioning within a defined geographic area, a GEC provides services to and fosters collaborative relationships among members of the health professions educational community. This educational community includes organizations or institutions (both affiliated and unaffiliated with the GEC or its parent organization) that sponsor formal and informal educational programs and activities for faculty, students, and practitioners in health care. The geographic area may be a State, or a portion of a State such as counties or a metropolitan area, or several States or portions thereof that the Center can expect to serve.

Significant Products: The **California GEC** has completed a pamphlet for relatives, friends, and other caregivers of persons with developmental disabilities. The pamphlet includes information on aging, resources and services and is available in English, Spanish, Korean, and Tagalog (Filipino). The **Finger Lakes GEC** has created a videotape that provides an overview of the conflicts which arise between families and nursing home staff as well as interventions to address the conflicts. The **Miami Area GEC** has produced an article entitled "The Aging Process: Legal and Ethical Issues in End of Life Decisions." The **Iowa GEC** is producing a series of pamphlets designed to be a ready source of practical information for long-term care practitioners on key clinical topics. All Info-Connect pamphlets are available in hardcopy and online form. The **Stanford GEC** has produced an educational program: "Understanding Depression and Dementia in Chinese American and Japanese American Elders," that is a teaching tool for bilingual community-based service providers and family caregivers, on the basic pathology and symptoms of depression and dementia, and manifestations and responses specific to Chinese and Japanese elders.

For more information, see the GEC Resource Directory at <http://kumc.edu/gecresource/>.

Funding Level: In FY 1999, there were 34 awards totaling \$7.2 million, with an average first year award of \$100,000 for a single institution and \$150,000 for a consortium of 3 or more institutions.

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MEXICO BORDER HEALTH COMMISSION

Funding Organizations: Health Resources and Services Administration (HRSA) and Centers for Disease Control and Prevention (CDC)

Partners: United States – Mexico Border Health Commission, Community and Migrant Health Centers and other community-based organizations.

Purpose: To implement “Diabetes: The Community in Action” leadership and advocacy training developed by CDC and HRSA in the U.S. – Mexico Border communities.

Target Population: Leaders/advocates from health centers, other CBOs, health departments, community outreach workers.

Types of Technical Assistance: Provide leaders with community health assessment, planning, networking, and evaluation skills.

Funding Level: Funding totaled \$60,000 in FY 2002 and an estimated \$60,000 in FY 2003.

Number of Caregivers Served: 60 leaders and advocates from Southern Arizona, the lower RioGrande valley of Texas are served annually.

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MEXICO BORDER HEALTH RESPONSE TO CAREGIVERS

Funding Organization: Health Resources and Services Administration (HRSA)

Partners: Centers for Disease Control and Prevention (CDC), Mariposa Community health Center, Nogales, AR and University of Arizona. Rural Health Office.

Purpose: To provide training and assistance to the Arizona Border Diabetes Education and Care project.

Target Population: Primary: Arizona Border Residents, with focus on Hispanic and Native American communities. Secondary: Residents of other Border States.

Types of Technical Assistance: Trained 25 community outreach workers/promotores de salud using a CDC-developed Spanish language curriculum. Trained 75 outreach workers/promotores at the National Promotores conference in San Diego, CA in August 2000.

Funding Level: FY 2001: \$60,000 from Bristol Myers, and Squibb; \$35,000 from HRSA; and \$35,000 CDC.

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THE FAMILY VOICES NETWORK OF FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

Funding Organization: Health Resources and Services Administration (HRSA)

Partners: State: Family Voices Chapters, Title V CSHCN programs/HP 2010 Implementation Teams, policymakers, the media, health professionals, MCHB funded discretionary grantees, including the newly funded Family-to-Family Health Information and Education Centers and Medical Home State Implementation grantees, families and family groups

National: MCHB; American Academy of Pediatrics; March of Dimes; National Center for Cultural Competence; Institute for Child Health Policy/University of Florida; Robert Wood Johnson Foundation; research efforts, such as with Brandies University and Mathematica Policy Research, Inc.

Purpose: Family Voices is a national grassroots network of families/caregivers, providers and friends speaking on behalf of children with special health care needs. The purpose of their current cooperative agreement is to consult with families and to build on existing family/professional partnerships, so that families of children and youth with special health care needs (CSHCN) have the information they need to make good decisions and to assure family-centered, community-based, culturally competent care and caregiver support for their children and youth. One component of this effort is to partner with MCHB in building the infrastructure and capacity for all states and jurisdictions through Family Voices state Chapters, coordinators and their partners, to eventually have viable Family-to-Family Health Information and Education Centers.

Statutory Cite: Social Security Act, Title V, 42 U.S.C. 701

Start Date: May 2001

Eligible Caregivers: Families with children and youth with special health care needs

Types of Technical Assistance: To assist states in the development of Family-to-Family Health Information and Education Centers which promote caregiver and family support, Family Voices:

- Provides a limited amount of funds to 50 states and 2 jurisdictions that comprise the Family Voices Network to develop the infrastructure for Family-To-Family Health Information and Education Centers;
- Designs, conducts and analyzes family service needs assessments;
- Adapts and provides training and technical assistance to the network and newly funded MCHB Family-to-Family Health Information and Education Centers;
- Is implementing a data collection system for states/centers to use; and

- Conducts regional workshops around implementation of the six core Healthy People 2010 measures for children with special healthcare needs (CSHCN)

Program Design: The Family Voices National Office staff in several locations around the country, work with Coordinators in every state, 10 Regional Coordinators, and consultants to identify network needs and the service needs of families. The National Office, regional coordinators and consultants also provide technical assistance and training to state coordinators and partners who then work with the new family centers, families and partners in their own states. Data collection, technical assistance and training activities include the six core Healthy People 2010 measures for children with special healthcare needs (CSHCN): families partnering in decision making, CSHCN receiving coordinated, ongoing, comprehensive care in a medical home; adequate public and private insurance; early and continuous screening; community based systems easily used by families; and, adolescents receiving services necessary to transition to all aspects of adult life.

Number of Caregivers Served: There are almost 40,000 Family Voices members - families of children with special health needs and friends and professionals who know and love our children.

Funding Level: \$725,000 a year, until 6/31/05.

Evaluation: Implements an evaluation and research plan that is focused on the health outcomes and systems development indicators using the six core measures.

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www.mchb.hrsa.gov
www.familyvoices.org

MENTORING AND FAMILY STRENGTHENING

Funding Organization: Substance Abuse and Mental Health Services Administration (SAMHSA)

Purpose: To learn how to reach more families and youth with cost-effective, science-based drug-prevention programs by:

- Developing knowledge of the processes and outcomes of widespread implementation of science-based parenting, family strengthening and mentoring programs to prevent drug use by youth and families
- Applying knowledge of effective models to reach the greatest number of persons offering services in multiple locations or to diverse target groups;
- Delineating the factors that influence decisions in adopting, adapting and implementing these programs;
- Determining the effects of the interventions on reducing alcohol, tobacco or illegal drug use as well as associated social, emotional, cognitive, and physical problems of participating parents, mentors and children.

Target Population: Policymakers, service professionals, and families.

Types of Technical Assistance: The Family Strengthening Program was funded initially in FY1999 to help communities identify cost-effective methods to disseminate information and provide training on effective, research-based, family-focused, prevention strategies and models. In FY2001, the Family Strengthening Model was incorporated into the Mentoring and Family Strengthening Program (MFS). The MFS program is designed to expand the science-based mentoring and family strengthening activities beyond their original target group, settings, and sites. This program builds directly upon the grantees' experience and expertise, assisting experienced grantees and program implementers to further disseminate and implement effective program models and approaches to the community at large.

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STATEWIDE FAMILY NETWORK AND SUPPORT PROGRAM TECHNICAL ASSISTANCE CENTER

Funding Organization: Substance Abuse and Mental Health Services Administration (SAMHSA)

Purpose:

- To provide support and information to Statewide Family Network grantees;
- To help Statewide Family Network Grantees explore funding opportunities to foster program sustainability beyond the lifetime of the grant program; and
- To strengthen organizational relationships by improving collaboration among families, advocates, networks, and coalitions dedicated to empowering families and strengthening their ability to participate in State and local mental health service-planning and health care reform policy activities on behalf of their children; and, to maintain effective working relationships with other State child-serving agencies including, mental health, other health services, education, child welfare, substance abuse, and juvenile justice.

Target Population: The target population is the 42 currently funded Statewide Family Network Grantees.

Types of Technical Assistance: The technical assistance center supports the Statewide Family Network grantees in developing support groups; disseminating information and technical assistance through clearinghouses; maintaining information, referral networks, and newsletters; sponsoring conference and workshops; outreach activities; serving as a liaison with various human service agencies, developing skills in organizational management and financial independence; and training and advocacy for children’s mental health services.

Funding Level: Grantees are funded on a competitive basis on a three-year cycle for \$300,000-\$600,000 depending on funding availability. Non-profit family run organizations (with family members comprising at least 51% of board members) are the eligible applicants.

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SECTION V

**CONSUMER EDUCATION, OUTREACH AND
ADVOCACY**

“BECAUSE WE CARE” CAREGIVER GUIDE

Funding Organization: Administration on Aging (AoA)

Purpose: The “Because We Care” Caregiver Guide offers a range of helpful tips, information and resources to support family caregivers in their caregiving roles. The guide covers areas including federal and national sources of information and assistance; descriptions of available caregiver support and personal care services and housing options; information on maintaining caregiver health and well-being, as well as the health and independence of the care receiver; and financial assistance resources.

Target Population: Family caregivers of people with disabilities of any age.

Types of Consumer Education, Outreach and Advocacy: The guide is available on the Administration on Aging website at www.aoa.gov/caregivers.

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ELDERCARE LOCATOR

Funding Organization: Administration on Aging (AoA)

Partners: The Eldercare Locator is administered by the National Association of Area Agencies on Aging in cooperation with the National Association of State Units on Aging.

Purpose: To help older adults and their caregivers find local services for seniors. The primary goal of the service is to promote awareness of and improve access to state, area agency and local community aging programs and services.

Target Population: Older Americans and their caregivers.

Types of Consumer Education, Outreach and Advocacy: Since 1991, the Eldercare Locator, a nationwide toll-free service, has helped older adults and their caregivers find local services for seniors. This service is also available on-line so that consumers can easily link to the information and referral (I&R) services of their state and area agencies on aging. Callers can speak to an Information Specialist who has access to a database of more than 4,800 entries. Individuals calling this service or using the website have access to state and local information & referral service providers identified for every ZIP code in the country. Individuals calling the Eldercare Locator can connect to more extensive information sources for a variety of services including: Alzheimer's hotlines, transportation, housing options, home health services, long term care ombudsman, home delivered meals, legal assistance, and adult day care and respite.

The toll-free Eldercare Locator number is (800) 677-1116. The Eldercare Locator is also available on-line at <http://www.eldercare.gov/>.

Funding Level: FY2002 \$1,199,000

Number of Caregivers Served: Serves on average 30,000 older persons and caregivers a month via the telephone and the website.

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NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM: CONSUMER EDUCATION

Funding Organization: Administration on Aging (AoA)

Purpose: To educate family and informal caregivers about the services available to support them in their caregiving role.

Target Population: Family and informal caregivers.

Types of Consumer Education, Outreach and Advocacy: A brochure on the National Family Caregiver Support Program contains information on eligible populations, services provided through the program, and supporting statistics for the program.

A “tip sheet” for family caregivers to use to identify areas where they may need support and information on how to locate and access this support.

A Public Service Announcement on public television about the National Family Caregiver Support Program aimed at caregivers who may need support services.

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STATE COUNCILS ON DEVELOPMENTAL DISABILITIES PROGRAM

Funding Organization: Administration on Developmental Disabilities (ADD)

Partners: Protection and Advocacy agencies, Centers for Excellence in Developmental Disabilities Education, Research and Services, State agencies, State and local non-profit advocacy organizations

Purpose: To address a wide range of issues including family supports and assistance on statewide bases to increase the independence, productivity, inclusion and integration of people with developmental disabilities and their families.

Target Population: Councils are uniquely composed of individuals with significant disabilities, parents and family members of people with developmental disabilities, and representatives of State agencies that provide services to individuals with developmental disabilities.

Types of Consumer Education, Outreach and Advocacy: Together, this group of individuals develops and implements a statewide plan to address the Areas of Emphasis of employment, education and early intervention, health, housing, transportation, child care, recreation, quality assurance, and formal and informal community supports.

Significant Products: The State Councils develop a State Plan of advocacy, capacity building, and systemic change activities including demonstration of new approaches to services and supports; outreach; training; technical assistance; supporting and educating communities; interagency collaboration and coordination; coordination with related councils, committees, and programs; barrier elimination; systems design and redesign; coalition development and citizen participation; and informing policymakers.

Funding Level: FY 2001 \$67,800,000. FY 2002 \$69,800,000.

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LIVE WELL LIVE LONG: STEPS TO BETTER HEALTH

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partner: American Society on Aging (ASA)

Purpose: To develop and disseminate “A Health Promotion/Disease Prevention Model for Older Adults,” a web-based tool designed for health promotion professionals, older adult consumers, and caregivers.

Target Population: Professionals who work with older adults.

Types of Consumer Education, Outreach and Advocacy: ASA is currently in the second year of a five-year project funded by CDC to develop and disseminate “A Health Promotion/Disease Prevention Model for Older Adults.” Five web-based modules (which may be found at <http://www.asaging.org/cdc>) will allow health promotion professionals to create a cafeteria style, customized manual that addresses local community health needs. Topics range from general principles of health promotion and disease prevention to specific conditions which impact older adults, such as medication management. ASA is collaborating with the Roybal Institute for Applied Gerontology at the California State University, Los Angeles, which is providing expertise related to elderly minorities.

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LIVING WELL WITH A DISABILITY

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partners: Department of Education (DoED)

Purpose: To serve as an educational and self-help curriculum which enables individuals with disabilities to benefit from increased knowledge regarding ways to take charge of ones health and daily living challenges.

Target Population: Individuals with disabilities.

Types of Consumer Education, Outreach and Advocacy: The Living Well with a Disability Program is a health promotion and wellness program for adults with physical disabilities. This is an eight-week workshop that introduces a process for setting and clarifying goals, as well as teaching skills for generating, implementing, and monitoring solutions. Goal setting and problem solving becomes the framework for developing healthy lifestyles and making the necessary connection between health and function. Keeping quality of life issues at the forefront, Living Well with a Disability teaches skills for:

- Preventing health problems,
- Keeping health problems under control,
- Physical conditioning or fitness,
- Developing and maintaining healthy relationships,
- Beating the blues,
- Information seeking and systems advocacy,
- Goal setting, and
- Making healthy lifestyle changes.

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NATIONAL DIABETES EDUCATION PROGRAM

Funding Organization: Centers for Disease Control and Prevention (CDC)

Purpose: The National Diabetes Education Program's objectives are:

- To increase public awareness of the seriousness of diabetes, its risk factors, and potential strategies for preventing diabetes and its complications.
- To improve understanding about diabetes and its control and to promote better self-management behaviors among people with diabetes.
- To improve health care providers' understanding of diabetes and its control and to promote an integrated approach to care.
- To promote health care policies that improve the quality of and access to diabetes care.

Target Population: Older adults with diabetes and their caregivers.

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PREVENTING INJURIES AMONG OLDER ADULTS

Funding Organization: Centers for Disease Control and Prevention (CDC)

Purpose: To prevent injuries among older adults related to falls, fires, driving, and elder abuse.

Target Population: Older adults

Types of Consumer Education, Outreach and Advocacy: *Toolkit to Prevent Senior Falls* – strategies to reduce fall risk among older adults; *Remembering When* – fire and falls prevention program developed with National Fire Prevention Association.

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SCREEN FOR LIFE

Funding Organization: Centers for Disease Control and Prevention (CDC)

Partners: Centers for Medicare and Medicaid Services (CMS) and National Cancer Institute (NCI)

Purpose: To inform adults over age 50 and caregivers on the value of regular colorectal cancer screening.

Target Population: Americans aged 50 and over.

Types of Consumer Education, Outreach and Advocacy: *Screen for Life* is a multimedia campaign created and implemented by CDC and its federal partner, the Centers for Medicare and Medicaid Services. This campaign is designed to promote colorectal cancer screening for men and women aged 50 and older. *Screen for Life* addresses common myths and educates Americans about the two ways that screening saves lives: by detecting colorectal cancer early or by finding precancerous polyps so they can be removed before they turn into cancer. *Screen for Life* materials are designed to be reproduced or adapted as needed, and they can be ordered or downloaded at www.cdc.gov/cancer/screenforlife. CDC also helps states incorporate state-specific information into their *Screen for Life* materials.

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MEDICARE BASICS

Funding Organization: Centers for Medicare and Medicaid Services (CMS)

Partners: Administration on Aging, National Council on the Aging, National Alliance for Caregiving, National Association of Area Agencies on Aging, National Federation of Independent Businesses, Small Business Administration

Purpose: To provide direct-to-consumer information needed to make or guide Medicare-related health care decisions, e.g. Medicare coverage, finding a specialist, choosing a nursing home, etc. The booklet is written in easily understood language and is organized around seven “identifiable moments” when caregivers must become involved because a decision must be made.

Target Population: Employees who are caregivers.

Types of Consumer Education, Outreach and Advocacy: This booklet will be distributed to employers and workplace intermediaries, e.g. National Federation of Independent Businesses, human resource services vendors (LifeCare, Ceridian) via partner websites and potentially through distribution of paper copies.

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WHEN EMPLOYEES BECOME CAREGIVERS: A MANAGER'S WORKBOOK

Funding Organization: Centers for Medicare and Medicaid Services (CMS)

Partners: Administration on Aging, National Council on the Aging, National Alliance for Caregiving, National Association of Area Agencies on Aging, National Federation of Independent Businesses, Small Business Administration

Purpose: The workbook contains ideas and materials on low cost and no cost programs on caregiving for employers and workplace intermediaries. Designed to facilitate employed caregivers' access to information, it will contain information for the employer or intermediary organization along with information to be provided to employees.

Target Population: Small and mid-size employers of employees who are caregivers.

Types of Consumer Education, Outreach and Advocacy: This workbook will be distributed to employers and workplace intermediaries, i.e. National Federation of Independent Businesses, human resource services vendors (e.g. LifeCare, Ceridian).

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FAMILY-TO-FAMILY HEALTH CARE INFORMATION AND EDUCATION CENTERS FOR FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Funding Organization: Health Resources and Services Administration (HRSA)

Partners: State and Local: Families, Family Groups and Family Voices coordinators; Family Resource Centers; Parent training and Information Centers; Title V Children with Special Healthcare Needs; Departments of Health and Education; Head Start; Child Care; Interagency Councils; Medicaid; State Children's Health Insurance; Children's Mental Health; Developmental Disabilities programs; legislative representatives; providers and professional provider organizations; Universities. National: Family Voices; American Academy of Pediatrics

Purpose: To establish a network of statewide centers run by families of children with special health care needs (CSHCN) to help other families with special needs children, including those of culturally diverse backgrounds.

Statutory Cite: Social Security Act, Title V, 42 U.S.C. 701

Start Date: June 2002

Eligible Caregivers: Families with children and youth with special health care needs

Types of Consumer Education, Outreach and Advocacy: Family-To-Family Health Care Information and Education Centers for Families of Children with Special Health Care Needs, are designed and supervised by families in partnership with State Title V CSHCN programs and other providers to offer:

- health and related information to families and providers for improving health decision-making;
- assistance on gaining greater access to and making better use of services within communities, including support for family caregivers; and
- educational and leadership opportunities to family members.

Program Design: Programs are designed around state specific needs but address the six core measures for children with special healthcare needs (CSHCN): families partnering in decision making, CSHCN receiving coordinated, ongoing, comprehensive care in a medical home; adequate public and private insurance; early and continuous screening; community based systems easily used by families; and, adolescents receiving services necessary to transition to all aspects of adult life.

Funding Level: There are currently six grants funded (CA, FL, ME, MN, TN, VT), for a total of \$544,713 this first budget period. Each grant is to be funded for four years. The goal is to eventually have a center in every state and jurisdiction.

Evaluation: Combination of grant specific, common data elements across grantees and MCHB developed performance measures

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STATEWIDE FAMILY NETWORK AND SUPPORT GRANTS

Funding Organization: Substance Abuse and Mental Health Services Administration (SAMHSA)

Purpose: The primary goals of the Statewide Family Network and Support Grants are:

- To strengthen organizational relationships by improving collaboration among families, advocates, networks, and coalitions dedicated to empowering families and strengthening their ability to participate in State and local mental health service-planning and health care reform policy activities on behalf of their children;
- To maintain effective working relationships with other State child-serving agencies including, mental health, other health services, education, child welfare, substance abuse, and juvenile justice.
- To identify technical assistance needs for family-controlled organizations and implement a strategy to meet those needs.

Target Population: Family controlled, nonprofit private entities, whose mission and scope of work have a statewide focus, serving families with children who have a serious emotional, behavioral, or mental disorder.

Types of Consumer Education, Outreach and Advocacy: The program supports State-level family network organizations to manage a set of activities to assist family members to participate in the development of policy, programs, and quality assurance activities related to children's mental health. Network activities may include: developing support groups; disseminating information and technical assistance through clearinghouses; maintaining toll-free telephone numbers, information and referral networks, and newsletters; sponsoring conference and workshops; outreach activities; serving as a liaison with various human service agencies, developing skills in organizational management and financial independence; and training and advocacy for children's mental health services.

Funding Level: Funding is on a three-year cycle for \$60,000 per year. In FY 2002, Statewide Family Network grants were awarded to 40 States, the District of Columbia and the Territory of Guam.

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